Making the most of respite care

This Help Sheet provides information for people living with dementia, their families and carers, about understanding and accessing respite services. It provides some practical suggestions for planning and using respite.

What is respite?
Respite is a form of support for all people living at home who have dementia, and their families and carers. For the person living with dementia, respite can be an opportunity to enjoy relationships and meaningful activities separate from their family or carer, and can be within their own home or elsewhere. Respite can also be a time where families and carers of people with dementia are able to sustain their personal wellbeing through work, leisure, interests and self-care.

“...I was glad of course to get out of the house and do something different...and Jill had time to herself to do things...” Person living with dementia

The person with dementia, and their family and carers, may have different needs for respite. Respite services support both the carer, and the person with dementia, throughout the changes in their lives.

The Government funds many different types of respite services to support people with dementia and their carers. Particular services are available in different areas, and access will depend on where you live and the eligibility of the person with dementia. To access respite services, an assessment will be conducted by a specialist assessment team who will determine eligibility and assess the needs of the person with dementia.

All respite services should offer flexibility to cater for individual needs, preferred types of respite, and personal circumstances, including people who are from Aboriginal and Torres Strait Islander communities, people with diverse cultural backgrounds or who speak languages other than English, and people who are lesbian, gay, bisexual, transgender and intersex.

The consumer should have choice and control over the planning and delivery of respite services.

Types of Planned Respite Services for people with dementia

- In-home respite
- Centre-based day respite
- Overnight or weekend respite
- Community-access respite
- Flexible respite
- Respite in a Residential Aged Care Facility

What respite is available?
To find out what respite services are available in your area there are a number of contact points:

Dementia Australia
National Dementia Helpline 1800 100 500
dementia.org.au

My Aged Care 1800 200 422
myagedcare.gov.au

The Carer Gateway 1800 422 737
carergateway.gov.au

Commonwealth Respite and Carelink Centres 1800 052 222

Emergency Respite Accommodation 1800 059 059

Veteran’s Home Care Assessment Agency
Metropolitan: 1300 550 450
Regional: 1800 555 254

(Please note that 1800 numbers are free except from mobile phones)
For people living with dementia under 65

Information is available through the Carer Gateway and Commonwealth Respite and Carelink Centres. The person with dementia who is under 65 and/or their carer can access services through the National Disability Insurance Scheme (NDIS).

The NDIS provides respite-like support via a program called ‘Support for Sustaining Informal Supports’.

Contact the NDIS help line on 1800 800 110 or ndis.gov.au

To find out about navigating the NDIS and what respite services are available for people with dementia who are under 65, contact Dementia Australia’s Younger Onset Dementia Key Workers on the National Dementia Helpline 1800 100 500 or dementia.org.au

Tips when considering respite

It is important to prioritise your needs and goals when thinking about respite. Things to consider:

What type of respite support is right for you?

- Is the type of service provided when you want it, for the time you want it?
- Do respite activities, staff and group members match the personal interests of the person receiving the respite service?
- Is the location and atmosphere safe, friendly and supportive?
- How are individual interests and wellbeing assessed, supported, discussed and reviewed?

There may be a waiting time, so it is important to plan ahead if you can.

Adjusting to Respite

It may take time to feel confident and comfortable using respite services. It can help to:

- talk with others about their experiences
- take short respite breaks before having longer ones
- share the initial experience with your respite worker in order to help everyone to get to know each other.

If you are not happy with the respite service talk to the service provider as it may be something that is easily adjusted or you may want to consider different respite options.

Building partnerships with staff

You can support building relationships with staff by sharing personal information from the beginning. Tell them what the person receiving respite likes and dislikes, their preferences when doing things, reactions to stress and what can help, significant life events, medical issues, medications and emergency arrangements.

It can also be useful for the person accessing respite to take with them a life story photo album or board or a meaningful personal object. These tools can aid conversations.

Complaints

If you are unhappy with the respite service and wish to raise any concerns, it is best to speak directly with the service provider, as it may be something that can be easily adjusted and can be resolved quickly in most cases. Alternatively, you may want to consider different respite options.

If you are uncomfortable to raise a complaint directly with the service provider or if things remain unresolved, you can contact the Aged Care Complaints Commissioner on 1800 500 294 agedcarecommissioner.gov.au

FURTHER INFORMATION

Dementia Australia offers support, information, education and counselling. Contact the National Dementia Helpline on 1800 100 500, or visit our website at dementia.org.au

For language assistance phone the Translating and Interpreting Service on 131 450